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ABSTRACT

The booklet addresses issues regarding the prevalence of mental retardation. Difficulties in obtaining prevalence figures are noted, specifically limitations of the use of the population curve. Prevalence studies are reviewed and methodological problems cited. Sex, age, and socioeconomic factors in the prevalence of mental retardation are described, as are effects of raising children in an economically disadvantaged home. Possible reasons for fluctuations in prevalence are offered, particularly the changing definitions of mental retardation. A concluding section summarizes prevalence information and suggests that the majority of people labeled mentally retarded fall into a gray area of "relative retardation." (CL)

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The Prevalence of Mental Retardation

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THE PREVALENCE OF MENTAL RETARDATION

Association for Retarded Citizens
ARC National Research and Demonstration Institute

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THE PREVALENCE OF MENTAL RETARDATION

Who are the nation's mentally retarded citizens? Where do they live and what do they do? How many American families are affected by mental retardation? Answers to these questions are basic to the pursuit of the Association for Retarded Citizens' three major goals: the prevention of mental retardation, the enhancement of the lifestyle and potential of mentally retarded persons, and the search for possible cures for disorders and conditions associated with mental retardation.

The field of statistics has truly come into its own during the last quarter century. Every year, methods of data collection and analysis become more refined, more sophisticated. Now, with the aid of computer science, statisticians can often project data far into the future with a reasonable degree of accuracy — or predict the outcome of an election after only a small percentage of the voters have gone to the polls.

Modern statistical methods have told us a great deal about the prevalence of mental retardation. Still, the nature of this disabling condition makes it extremely hard to pin down — even with the most modern tools and procedures. Unlike blindness and obvious birth defects, in most cases mental retardation is an almost invisible disability. A great many mildly retarded persons simply grow up, blend into the general population and disappear forever from the statistician's reach. To compound the problem, professionals do not always agree on the definition of mental retardation. Thus, even under controlled, ideal testing conditions, prevalence figures from one researcher may differ significantly from those of his of her colleagues.

The Search for Mentally Retarded Citizens

A survey of community clinics and agencies is an established method of identifying mentally retarded persons. However, such surveys can only identify those persons who have come into contact with the organization in question. Unfortunately, many mentally retarded persons go unnoticed by agencies and clinics for a variety of reasons. Theoretically, the public school systems of our nation offer a natural arena for such a task. Since most children in the community are filtered through the school system, the statistician should have the numbers he needs to gain an

accurate idea of the prevalence of mental retardation. But — what if 10 different schools test for mental retardation — using 10 different definitions for this condition? Cutoff points for mental retardation range from IQ 70 to IQ 80. Until 1973, the American Association on Mental Deficiency placed the cutoff point at 85. A range of 15 points makes a great deal of difference in the overall picture. *One* point can make a difference to the future of a person labeled as mentally retarded. To further complicate matters, a variety of tests are typically employed to measure intelligence, and the IQ estimates that they produce may vary considerably.

The Limitations of the Curve

In theory, it should be relatively easy to predict the prevalence of mental retardation through a regular "population curve" (i.e., normal distribution curve). If it is assumed that IQs follow a normal curve, between 2 and 3 percent of the population should fall below 70 (the approximate cutoff point accepted by the American Association on Mental Deficiency) and about one person in a thousand should have an IQ below 50.

Unfortunately, the curve is not overly useful in establishing the prevalence of mental retardation. A low IQ is *not* the only criterion. A mentally retarded person must also exhibit impaired adaptive behavior. A substantial percentage of persons with IQs below 70 show little adaptive deficit. Simply put: *Not everyone with a low IQ is retarded.* Furthermore, while this type of curve presents a reasonable picture of intellectual development within the "normal" range, the farther a given IQ is from the average, the more the curve errs in predicting its prevalence. As it happens, there are actually a great many *more* persons in the moderate, profound and severe ranges of mental retardation than the curve would predict.

A Survey of Prevalence Studies

As mentioned, the most common method of determining prevalence involves surveying various community agencies that would normally come in contact with mentally retarded persons. A typical example of such a study was done in Onondaga County, New York.[1] This survey queried all public and private agencies that would have records of cases of retardation. The request specified confirmed or *suspected* cases in persons who

were under 18 years of age. The results: 3,787 cases, resulting in a prevalence rate of 35.2 per thousand of population (3.52 percent). Another study[2] yielded a prevalence figure of 2.36 percent among school-age children — considerably lower than the Onondaga study. This study, which took place in Hawaii in 1956, strictly defined the bounds of mental retardation. If group IQ scores were available, students with IQs below 65 were considered retarded only if both reading and arithmetic skills were three years below grade level. First and second graders were classified as retarded only if they could not read a pre-primer and do sums below 10. Kindergarten students were considered retarded only if they were unable to succeed in readiness activities in language and numbers. The strict criteria established in this study may well have *underestimated* the prevalence.

Another study[3] included development of an adaptive behavior scale that was used in testing 2,661 households. These households were a representative sample of various ethnic, racial, geographic and socioeconomic groupings. The scale was administered to 6,907 people, including 1,026 preschoolers, 1,875 school-age children and 4,006 adults. Adaptive behavior scales were varied according to each age group. In addition, the Stanford-Binet intelligence test was given to 660 individuals randomly selected from the nearly 7,000 persons taking part in the adaptive behavior tests. Thus, this was one of the few prevalence studies that actually measured both adaptive behavior and intelligence independently — as required by the current definition of mental retardation. The result of these tests: a mental retardation prevalence of 3.47 percent. This figure is quite comparable to other prevalence studies. It also points out that *IQ alone cannot be used to measure mental retardation*. As mentioned earlier, as reflected in these tests, a great many people who have low IQs have no obvious impairment in adaptive behavior. Mercer, who conducted the study, called these people the *quasi-retarded*. Similarly, there were a number of people who had problems with adaptive behavior, but whose IQs were not in the mentally retarded range. These persons were identified in the study as *behaviorally maladjusted*.

Farber[4] summarized a number of the best prevalence studies available. Taking into consideration differences in criteria, perhaps the best general summary of this research indicates that *2.5 to 3 percent of the general population is mentally retarded*.

Based on the 1980 census, this estimate ranges from 5.6 to 6.7 million. Incidentally, based on this and similar figures, the prevalence of mental retardation is exceeded by only four other major health problems: mental illness, cardiac diseases, arthritis and cancer.

Of the total retarded population, the vast majority are mildly retarded. It is estimated that only about 15 percent of all retarded persons have IQs below 50. For example, the President's Panel on Mental Retardation estimated that 86.7 percent of the retarded population was mildly retarded, 10 percent was moderately retarded, and only 3.3 percent was severely or profoundly retarded. Several other studies have confirmed these general estimates. For example, Abramowicz and Richardson[5] reviewed 27 prevalence studies of children with IQs below 50. Almost all of these studies reported a prevalence rate of between three and five per thousand (.3 to .5 percent), and they concluded that the "true" estimate was approximately four per thousand (.4 percent), a figure quite consistent with the estimate made by the President's Panel on Mental Retardation. This means that there are nearly 900,000 people in the United States whose intellectual functioning is so impaired that they will very likely never lead fully independent lives.

Differences in Prevalence in Different Segments of the Population

While mental retardation strikes all segments of the population, it is far more likely to occur in some groups than in others. These differences in prevalence provide us with some important insights into the nature of mental retardation.

Sex: All of the prevalence studies summarized by Farber found more mentally retarded males than females. The exact proportion of males to females varied somewhat, but the overall results are quite clear: The ratio of mentally retarded males to females is around 3-to-2. In other words, about 60 percent of mentally retarded persons are males; 40 percent females.

Why is there a disproportionate difference? First, for reasons presently unknown, unborn males are more susceptible to various kinds of trauma. Male babies are more likely to be born prematurely, and more likely to suffer various kinds of brain

damage. Male fetuses are more likely to be aborted or miscarried. Even after birth, males are more susceptible to the various dangers of their physical environment.

Still, biological differences probably account for only a part of the male/female ratio of mental retardation. Psychological factors also enter the picture. Parents treat boys and girls quite differently, a factor that might contribute to differences in mental functioning. For instance: Parents are frequently more tolerant of aggressive and "acting out" behavior among boys. This means boys are less likely to apply themselves to schoolwork and other intellectual pursuits.

Another contributing factor is that boys who are doing poorly are more likely to be *diagnosed* as mentally retarded than are girls. Boys who are not doing well in school tend to call attention to themselves and become "behavior problems" — girls having difficulties tend to sit quietly in the back of the class. Since many teachers prefer quiet children to disruptive children, boys are more likely to be referred to the school psychologist for testing, or sent to the principal for disciplining. *This does not mean there are more mentally retarded boys than girls — it simply means that a poorly functioning boy is more likely to come to the attention of school or medical authorities.* Evidence for this argument comes from the Mercer study described above. In one aspect of this study, Mercer utilized the traditional approach of surveying all likely agencies within the community. Virtually all types of agencies contacted reported more mentally retarded males than females. However, in Mercer's field study, where adaptive behavior scales and an intelligence test were administered to a representative sample of the community, the sex difference disappeared. Mercer found almost exactly equal numbers of males and females. However, the ratio of behaviorally maladjusted (those who failed the adaptive behavior scale but not the intelligence test) males to females was almost 2-to-1.

Prevalance Differences at Different Ages: Most studies find clear differences in the prevalence of mental retardation at different ages. For example, in the Mercer study: Out of 812 people reported as mentally retarded by agencies contacted, only 7 percent were under 5... 72 percent were 5-19... 21 percent were over 19. Comparing these figures to general population figures: Thirteen percent are under 5... 39 percent are between

5 and 19... 48 percent are 20 or older. In other words, there were about half as many mentally retarded preschoolers and half as many mentally retarded adults — but twice as many mentally retarded school-age children as would be predicted *if mental retardation were evenly distributed across the ages studied.*

Most other prevalence studies report a similar phenomenon — a small prevalence of retardation among preschoolers, a gradually increasing number of mentally retarded among school-age children, reaching a peak at about age 13, then a sharp decrease in prevalence among the population older than 16.

If we accept the traditional clinical approach to mental retardation — that is, that mental retardation is an essentially permanent condition originating from birth or shortly after, then this finding is disconcerting; we would expect to find the prevalence of retardation to be about the same among *all* age groups, making minor allowances for the few who become retarded during the school years as a result of accidents, or the differential death rates of mentally retarded people. However, this is clearly not the case.

How do we explain this phenomenon? One answer is that numerous cases of mental retardation among preschoolers and adults go undiagnosed. When mentally retarded youngsters attend school, they are likely to be discovered by teachers or school psychologists. However, after they leave school, agencies dealing with people who are mentally retarded lose contact with them. Thus, they are no longer counted in prevalence studies. In other words: The proportion of the population that is mentally retarded *does not differ much from one age group to another; the differences in prevalence found at different ages are the result of inaccurate reporting procedures.* This conclusion is supported by the Mercer study, which found that when intelligence tests and adaptive behavior scales are actually administered to a large number of randomly selected people, the prevalence of mental retardation is relatively constant across age groups.

A second interpretation of this phenomenon is based on the fact that a person can be retarded in some situations, but not in others. One of the defining characteristics of mental retardation is an impairment in adaptive behavior, and this impairment must be culturally defined. For example: Since schools make intellectual

demands on the individual, many people who are considered retarded in school are no longer "retarded" once they leave this academic setting. Certainly, those persons are still mentally retarded, but they are no longer faced with the direct intellectual challenge of the classroom.

This interpretation is supported in a classic study by Charles[6], who followed up 151 cases of people who had been labeled as mentally retarded during their school years. At the time of the study, the average age of the subjects in the group was 42. The majority of these people were leading independent, productive lives. About 80 percent were married, only slightly less than the national average. Over half owned, or were buying, their own homes. Thirty-three percent of the males and 42 percent of the females had been entirely self-supporting since school. At the time of the study, 83 percent were employable, and usually were actually employed. Occupations of the persons studied varied greatly: While many were unskilled laborers, quite a few were found in management, clerical or sales positions. Only nine were institutionalized. Sixteen percent had died — a figure considerably higher than would be expected by chance. This study demonstrates quite conclusively that many people labeled as mentally retarded by their schools go on to lead independent, useful lives within the community.

Socioeconomic Factors in the Prevalence of Mental Retardation

There is a clearly established relationship between poverty and mental retardation. Malnutrition, lead poisoning and lack of prenatal care are only a few of the factors that may contribute to the disproportionate frequency of mental retardation among America's poor. Not surprisingly, then, children from economically disadvantaged families tend to score lower on IQ tests than children from more affluent families. Some early studies[7] showed that children of professional men had an average IQ of 116, while children of day laborers and farm owners had IQs of 96 and 95, respectively.

A number of conditions in a child's pre- and postnatal environment have been found to contribute to a lower level of intellectual functioning. Most of these conditions are found far more frequently among the poorest groups in our society.

★ Lead poisoning from eating paint chips is almost exclusively a condition associated with poverty.

★ Persons who live in poverty areas are less likely to receive adequate medical care — a factor that contributes to a higher rate of infant mortality, and a higher rate of birth defects and other conditions associated with brain damage.

★ Poor mothers are less likely to receive rubella innoculations.

The Social and Psychological Environment of the Poor: Some professionals in the field of mental retardation feel that a major cause of impaired learning abilities among the poor is sensory deprivation. Poor children have fewer toys to play with — and fewer objects of *any* kind to stimulate their imaginations and focus their attention on experiences outside of their environments. On the other hand, some experts feel that poor children may be *over* stimulated by crowded living conditions — so much so that they may learn to ignore stimuli that might contribute to their development.

Preschool years are vital, formative years for a child. Ordinarily, "advantaged" children receive a great deal of attention during this time. Mothers talk to their children and read them stories. Children explore their environments, ask questions — and get answers. This type of attention prepares the child for success in school — children who receive such stimulating training at home are consistently higher achievers in the academic setting.

Language provides the symbols needed for more abstract thought, and the verbal expression of those thoughts. Again, the advantaged child is more likely to receive early exposure to a more elaborate form of language — more complex sentence structure, a larger vocabulary, etc. A child with the ability to understand more complex patterns of speech, and communicate that understanding to others, has a distinct advantage in the classroom situation over the less privileged child.

Raising Children in the Economically Disadvantaged Home

Many authorities feel that the manner in which poverty-level families deal with inter-family relationships has a great bearing on

a child's ability to learn. For example: Discipline tends to be authoritarian rather than interactive. The father and mother are more likely to say "Do it because I say do it," than explain the reasons behind their request. In studies comparing the interactions of middle-class and disadvantaged mothers with their children, the middle-class mothers had a 60 percent higher verbal output than their less affluent peers. In addition, they tended to use longer and more complex sentences, and more abstract words. The middle-class mothers used more rational, person-oriented means of control, while the poverty-level mothers appealed to authority. For instance, a middle-class mother told her child why he was going to school, how to act, what to do, etc. The disadvantaged mother concentrated on "doing what the teacher tells you to do."

Other studies point out the relationship between economic deprivation and the prevalence of children with minor or major learning disabilities. On problem-solving tasks involving their children, mothers in the lower socioeconomic group were more likely to intrude physically, while middle-class mothers tended to help with leading questions. Various other studies have reached the same general conclusion: Differences in child-rearing styles may be an important contributing factor to the generally poorer school performance, and higher incidence of mental retardation, among socioeconomically deprived families.

Changes in Prevalence, Changes in Definition

Contemporary studies show a higher prevalence of mental retardation than studies at the turn of the century. Farber summarized seven projects completed between 1906 and 1916. The results: prevalences ranging from 3.82 to 7.35 per thousand. There is a marked difference between these figures and the 35.2 per thousand reported earlier.

What is the reason for such discrepancies? Obviously, statistical research has improved over the years. Studies nearly eighty years ago were not nearly as thorough as they are today, and it is quite likely that a great many cases of mental retardation were missed. Still, the primary reason for this discrepancy lies in the changing definitions of mental retardation. Before the age of widespread testing and sophisticated methods of diagnosis, only the most obvious forms of mental retardation were recognized. It is quite

probable that a great many individuals now considered as mildly retarded — the largest proportion of the mentally retarded population — merely disappeared into the simpler society of the day. It is becoming increasingly difficult to cope with the demands of daily living. Moreover, it is no longer quite so easy to go unnoticed in the community. This is the age of the statistician. We have become a nation of counters and labelers. We like to know who everyone is, and where they are. While this trend has obvious drawbacks, it does mean that those people who need help are now more likely to get it. Thus, an ever-increasing number of mildly retarded individuals have become a part of the count.

However, nearly all trends reverse themselves, and it is likely that this one will be no exception. There is growing opposition to schools "labeling" people as mentally retarded. In the future, it is possible that the term "mentally retarded" will be reserved for only the most severely disabled people.

A Summary: The Prevalence of Mental Retardation

Research on prevalence clearly illustrates many of the problems concerning our current conception of mental retardation. The difficulties in identifying mentally retarded persons make it nearly impossible to arrive at totally accurate figures. Moreover, professionals in the field don't always agree on the definition of retardation — a factor that makes it difficult to arrive at universally acceptable figures on prevalence.

There is little disagreement on the criteria for defining moderate, severe and profound mental retardation. However, authorities are not always in agreement on how to define the largest proportion of the mentally retarded population — those generally termed as mildly retarded. Society itself seems to have difficulty with this distinction. For example: Some children have enough problems with school subjects to be labeled as mentally retarded by the school system itself. However, when these children go home at the end of the day — or leave school permanently — they function relatively well in society. Thus, while school personnel and classroom peers may consider such

children as mentally retarded, family, friends and neighbors outside the school setting may consider them merely "slow."

Surveys of organizations, agencies and clinics identify only those persons who have come into contact with those organizations. Varying testing methods utilized by different schools and agencies tend to cloud the issue of what is mental retardation. Current cutoff points for mental retardation range from IQ 70 to IQ 80.

A low IQ, of course, is not the only criterion for mental retardation. A mentally retarded person must also exhibit impaired adaptive behavior. Only those studies which measure both intelligence and adaptive behavior meet the demands of the current definition of mental retardation.

Current prevalence figures range from 2.36 percent to 3.52 percent. One summary of the best prevalence studies available indicates that 2.5 to 3 percent of the general population is mentally retarded — based on the 1980 census, this totals from 5.5 to 6.7 million people.

According to one report, the vast majority of the retarded population, an estimated 87 percent, is mildly retarded. Roughly 10 percent is moderately retarded, and only 3 percent is severely or profoundly retarded.

While mental retardation strikes all segments of society, it is far more likely to occur in some groups than in others. Prevalence studies indicate that there are more mentally retarded males than females — perhaps a 60-40 ratio. Male susceptibility to traumatic experiences such as premature birth, brain damage, and various dangers after birth, account for some differences in the ratio of mental retardation. However, there is some evidence that parental and teacher attitudes toward male "behavioral problems" have a definite bearing on prevalence figures. Both parents and teachers prefer quiet children to disruptive children. Thus, the boy who expresses his anger or aggression is more likely to be sent to the school psychologist or the principal. Apparently, there *is* a difference between the prevalence of mental retardation in males and females — but the difference may not be as marked as some authorities have reported.

Is mental retardation more prevalent in one age group than in another? While some studies indicate a preponderance of retardation in some age groupings, other researchers feel that differences in prevalence at different ages are the result of inaccurate reporting procedures. As mentioned, individuals who appear mentally retarded in some settings do not appear retarded in others. One study showed that individuals labeled as mentally retarded in school went on to lead independent, productive lives in the community.

There is an obvious relationship between poverty and mental retardation. Malnutrition, lead poisoning and a lack of proper medical care are only a few of the factors that may contribute to the disproportionate incidence of mental retardation among the disadvantaged members of our society.

Lead poisoning is almost exclusively associated with conditions of poverty. Inadequate medical care contributes to a higher rate of infant mortality, and a higher rate of birth defects.

There is a marked difference between current prevalence studies and studies completed during the early 1900s. At least two factors account for these differences: improved methods of research and changing definitions of mental retardation. Many mildly retarded individuals who would have blended into society some years ago are now being counted before they take their places in the community.

In the future, it may be that the term "mentally retarded" will be reserved only for the most severely disabled individuals. An ongoing characteristic of mental retardation is the fact that, in one respect, the more we learn about this disability, the harder it is to define. An ever-increasing number of mildly retarded persons are taking their places in society. Probably the majority of the people in this country who have been labeled as mentally retarded fall into that gray area of "relative retardation."

Except for the most extreme cases, mentally retarded persons refuse to fit neatly into one category or another. Methods of testing intelligence frequently fail to show how a particular individual has adjusted to his environment and made a place for himself.

The presence of this large, gray area of mental retardation makes it next to impossible to accurately determine the number of mentally retarded individuals living in society. Still, the fact that there *is* a problem in determining the prevalence of mental retardation is a healthy sign for those concerned with the welfare of mentally retarded citizens: We are becoming less aware of the differences in people, and more aware of the similarities.

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